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Launch of the ADPKD Patient Routemap: an interactive new resource to help empower patients and families

ERA-EDTA Congress 2018 sees the launch of the ADPKD Patient Route Map, an interactive resource designed to help educate and empower people affected by autosomal dominant polycystic kidney disease (ADPKD).

'The ADPKD Patient Route Map is a great example of how patients and experts can work together', says Tess Harris, PKD International President and an ADPKD patient. 'Ultimately the idea is to help everyone affected by ADPKD cope better with the disease and get all the care, support and information they need, at the right time'.

The ADPKD Patient Route Map is freely available to download from the PKD International website (www.pkdinternational.org/adpkd-route-map).

The Route Map explains the types of care and support that patients and families should expect from their health service. The aim is to help patients and carers to manage their own health with their healthcare team, to talk about ADPKD with their nephrologist, to participate in making decisions about their own care, and to make the best use of available care and support services.

The Route Map was developed jointly by the European ADPKD Forum (EAF). EAF is an international group of experts from the fields of nephrology, genetics, hepatology and advocacy, and PKD International, the international ADPKD patient support group alliance.

The idea for the Route Map came from an EAF Round Table meeting involving patients and representatives from various European-level societies of medical specialists involved in ADPKD care and kidney patient organisations, in January 2016. The resulting '[EAF Multidisciplinary Position Statement on ADPKD Care](#)', recently published in the April edition of *Nephrology Dialysis and Transplantation*, explains the principles and evidence base for the Route Map.

The [Route Map](#) presents in lay terms what ADPKD is, how it is diagnosed, assessed and managed over the course of the disease – including self-care measures that patients can take to stay as healthy as possible. It also covers kidney complications (such as cyst infections and kidney stones), pain management and major non-kidney manifestations (such as liver cysts). It gives advice on issues such as genetics and genetic testing, family planning, and coping with the effects of ADPKD on wellbeing, work and finances. Finally, it outlines opportunities for patients to participate in research, registries and highlights the role of the European Rare Kidney Disease Network (ERKNet).

As Prof. Albert Ong (Sheffield, UK), a co-author of the Route Map put it: 'We've tried to map out ADPKD along the course of a lifetime. What's great about the Route Map is that it's not just a book of facts – it's attractive and interactive, allowing people to look at different topics according to the different stages of their own journey.'

The Route Map allows readers to reveal further information on key topics and messages of advice, experience and support provided by patients and their family members across Europe. Checklists are provided to help patients and families get the most out of consultations, and healthcare teams ensure that patients are always at the centre of their care pathway.

Co-author Dr Vicente Torres (Rochester, MN, USA) said: 'The Route Map should be very useful to nephrologists – to help us to inform and empower our patients and to ensure that our services are truly patient-centred.'

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